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Special Issue on Designing with and for Users on the Autism Spectrum

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   Marc's research is centered around participatory design, user experience design and enabling technologies. He leads the "Technologies for Health and Wellbeing" research group at Leeds Beckett University and has been Principal Investigator for two EU-funded research projects on supporting autistic university students (www.autism-uni.org, www.imageautism.com), both of which used participatory design approaches.

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EDITORIAL

Autism is a lifelong neurodevelopmental condition that affects how a person communicates with and relates to other people, and to the world around them. It is estimated that around 1 in 68 people are autistic (Christensen et al 2016). Autism is also a spectrum condition, which means that it affects different people in different ways. Some autistic people have significant communication impairments and some also have profound learning and cognitive disabilities (Fombonne et al 2011). However, a substantial proportion is of average or advanced intellectual ability and generally leading an independent life.

Autism can lead to ways of thinking and behaving that appear rigid or repetitive, and to difficulties in concentrating and processing information in typical ways (American Psychiatric Association 2013). When designing products for this population, autistic characteristics have to be considered. Autistic people typically welcome structure, both in their daily routines and their social interactions (Howlin 2004). It has been argued that interactive systems should equally be designed in a clear and uncluttered way, reducing complexity (cf. Fabri and Andrews 2016). However, capabilities and

individual preferences can vary widely across the autism spectrum, and what works for one group may not be universally applicable.

The importance of end-user participation in the design and development process has been widely acknowledged (Greenbaum 1993, Sanders and Stappers 2008, Rogers et al 2011). Over the years, different terms have been used to describe such involvement, e.g. user-centred design, participatory design, co-design, informant design, design thinking or emancipatory design. Whilst there is much overlap and terms are often used interchangeably, approaches can differ in how they view the role, privilege and empowerment of the stakeholders involved. For this Special Issue, we were particularly interested in approaches that involved autistic people in a highly inclusive and empowered way, as part of the design team and as experts of their own lived experiences.

This may present new challenges to the designers of technology. Established participatory design practices may prove challenging to apply as autistic users may find it difficult to express their preferences clearly. They may also struggle with the roles typically assumed in participatory design approaches that rely on active user involvement, participation in co-creation sessions and prototype testing and refinement. On the other hand, there may be innovative participatory design methods that capitalise on autistic users' strengths and interests. Therefore, due to the wide variances in skills and abilities demonstrated by persons with autism, for best results a robust set of user participatory strategies need to be considered prior to selection and implementation.

This Special Issue focuses on examining such methods, approaches and theoretical underpinnings for effective participation of autistic end users. We received 17 submissions to the Special Issue. After three rounds of rigorous reviews by an international panel of reviewers, five papers were eventually accepted for publication. We would like to thank the panel of reviewers for the thoughtful and critical comments they provided, and to journal editors Constantine Stephanidis and Gavriel Salvendy for giving us the opportunity to guest edit this Special Issue.

The accepted papers present important examples of good practice for how research, design and development can be conducted with full participation of autistic end users – not just in the final stages of evaluation but from the earliest point of technology conception and ideas generation. Some papers included in this Special Issue involve end users only in the later stages of the design process. However, we feel that the methods employed by these researchers are notable examples of good practice.

Much previous research in this area has been dominated by work with autistic children. We are therefore particularly delighted that two out of the five papers are concerned with participatory design with autistic adults, a growing area of interest and importance.

The first paper in this issue entitled "Thinking Outside The Box - Designing Smart Things with Autistic Children" by Frauenberger, Spiel and Makhaeva, uses long-term participatory design processes to develop individual solutions for nine different autistic children. The research employs a number of different methods, informed by the capabilities, strengths and preferences of these children. The authors contribute to the current discussion around technology for disabled people by proposing a new, alternative approach to participatory design and its evaluation.

Martin, Cupeiro-Durán, Pizarro-Casas, Roldan-Alvarez and Montero de Espinosa provide the second paper entitled " 'Today I tell...' a comics and story creation app for people with autism spectrum condition". Their paper describes the design and development of an app to help autistic people express themselves through the creation of stories and comics. The focus is on involving multi-disciplinary design teams as well as a wide range of stakeholders, in order to maximise functionality, usability and accessibility of the final product.

In their paper “A tablet computer-assisted motor and language skills training programme to promote communication development in children with autism: Development and pilot study”, Weisblatt and colleagues reflect on the creation of Point OutWords, which involved co-creation activities both with autistic children and with therapists. The authors adapted their design process to the needs of non-verbal participants, with a focus on strengths such as receptive language skills.

The fourth paper, entitled “Participatory Design of a Hybrid Kinect Game to Promote Collaboration between Autistic Players and their Peers” by Sturm, Kholodovsky, Smith, Arab, Asanov and Gillespie-Lynch, reports on the design of a two-player game that encourages complex emotion recognition and collaboration between autistic people and their neuro-typical peers. The game was co-designed, evaluated and iteratively improved by autistic college students, their peer mentors, a psychologist and computer scientists. What makes this approach unique is the involvement of autistic programmers who contributed to the software development. The game requires two players to cooperate and interact with each other, not just within the game environment but also in the real world. The authors share their insights and lessons learned to guide future participatory design projects.

Roper, Dutka, Cobb and Patel provide the final paper of this issue, entitled “Collaborative virtual environment to facilitate game design evaluation with children with ASC”. In their research, challenges related to face-to-face communication are alleviated through the use of collaborative virtual environments where participants are represented by avatars. This presents opportunities for participatory design activities taking place in a virtual environment, allowing autistic people to contribute equally and in line with their preferred communication styles and abilities.

We hope that this Special Issue inspires future research around the participation, empowerment and emancipation of end users on the autism spectrum, with a specific focus on capitalising on autistic strengths. The ultimate goal, in the guest editors’ opinion, is to help researchers and designers reflect on their position of power and privilege in the design process, and increasingly to step aside to let autistic end users become true co-creators of the products that are ultimately meant for them to use, enjoy and sometimes greatly rely on.

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